

This leaflet explains why information on use of medicines and illness in pregnant women is recorded by UKTIS, how this information is used, and how, if you wish, you can see your information.

Medicine use in pregnancy

Medicine use during pregnancy may be necessary for the health of the mother and her ability to carry a pregnancy. However, some medicines when taken during pregnancy increase the chance of miscarriage, birth defects, learning difficulties or other problems in the baby that may only be noticed later on in life. Women and health care providers therefore need up-to-date information based on scientific studies when deciding about use of a medicine during pregnancy.

What is the UK Teratology Information Service (UKTIS)?

UKTIS was established in the 1983 following the thalidomide tragedy of the 1960's.

UKTIS role is to:

1. Advise health care providers on medicine use in pregnancy
2. Provide information on whether a medicine taken by the mother might harm an unborn baby
3. Collect and analyse how pregnancies reported to UKTIS end
4. Undertake research to improve the use of medicines in pregnancy

Why does UKTIS collect patient information?

Pregnant women are generally not included in clinical trials or studies of medicines unless the medicine being studied is already considered to be safe to use in pregnancy. The safety of many medicines is however unknown. Collecting information on the babies of women who take a medicine(s) in pregnancy, or who had an illness that needed treatment during pregnancy, is therefore very important for improving the treatment of women and medicine use during pregnancy in the future.

To do this, UKTIS need to record your and your baby's personal details. UKTIS can then follow-up your baby's health after birth or how your pregnancy ends.

What information does UKTIS collect?

Your clinical team will be asked to provide UKTIS with information about you, your pregnancy and your baby. This will include you and your baby's name, address, NHS number and date of birth, as well as information about your pregnancy, your health and your treatment.

UKTIS has the government's permission to collect this information. To get a complete picture we may also link this information to your, or your child's, other health records and may share it with the doctors and nurses who are looking after you or your child.

Benefits of UKTIS collecting this information

- identification of medicines that are harmful to a baby in the womb
- improved treatment of pregnant women in the future
- helping women and doctors to make a decision, based on scientific facts, about the best treatment during pregnancy
- to support research on the use of medicines in pregnancy

Collecting your information may not benefit you directly, but could help other patients and families in the future.

Can I report my pregnancy to UKTIS directly?

Yes. In 2014, UKTIS launched a patient focused website, '***bumps - best use of medicines in pregnancy***'. You can provide information directly to UKTIS by creating your own password protected '***my bumps record***' via our ***bumps*** website (www.medicinesinpregnancy.org).

Who sees the information UKTIS collects?

There are very strict regulations controlling access to personal information. You and your child's details will only be available to clinical staff treating you or your child, and to those who work in UKTIS. Information that might identify you can only be used by researchers if they have your consent or legal and ethical permission to do so.

Information is confidential

Making sure your personal information is private and confidential is very important. UKTIS follows a strict policy on security and confidentiality that is available to the public. The service conforms to the requirements of legislation on data protection. If you would like to see the information we have about you, we can give this to your doctor for them to share with you.

How is information collected by UKTIS used to help pregnant women?

UKTIS periodically review the information they have collected for a specific medicine, along with any published scientific studies. UKTIS then write a scientific summary of the evidence that is available. UKTIS summaries are available at no charge to NHS health care providers in the UK.

UKTIS also produce leaflets for patients in which the information in our scientific reviews. These are freely available on our website (www.medicinesinpregnancy.org).



More about UKTIS

You can get more information by:

- asking your clinical team
- visiting the UKTIS website www.uktis.org for information on UKTIS
- visiting our 'bumps' website www.medicinesinpregnancy.org for information on how a specific medicine might affect a pregnancy or child after birth



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THE UK TERATOLOGY INFORMATION SERVICE

What it is and the benefits of reporting to UKTIS

